

The National Cancer Institute and Office of Rare Diseases

Synergizing Epidemiologic Research on Rare Cancers
Hyatt Regency Hotel, Bethesda, MD
May 10–11, 2007

Sarcoma Working Group

Chair: Sharon Savage

Co-Chair: Vaurice Starks

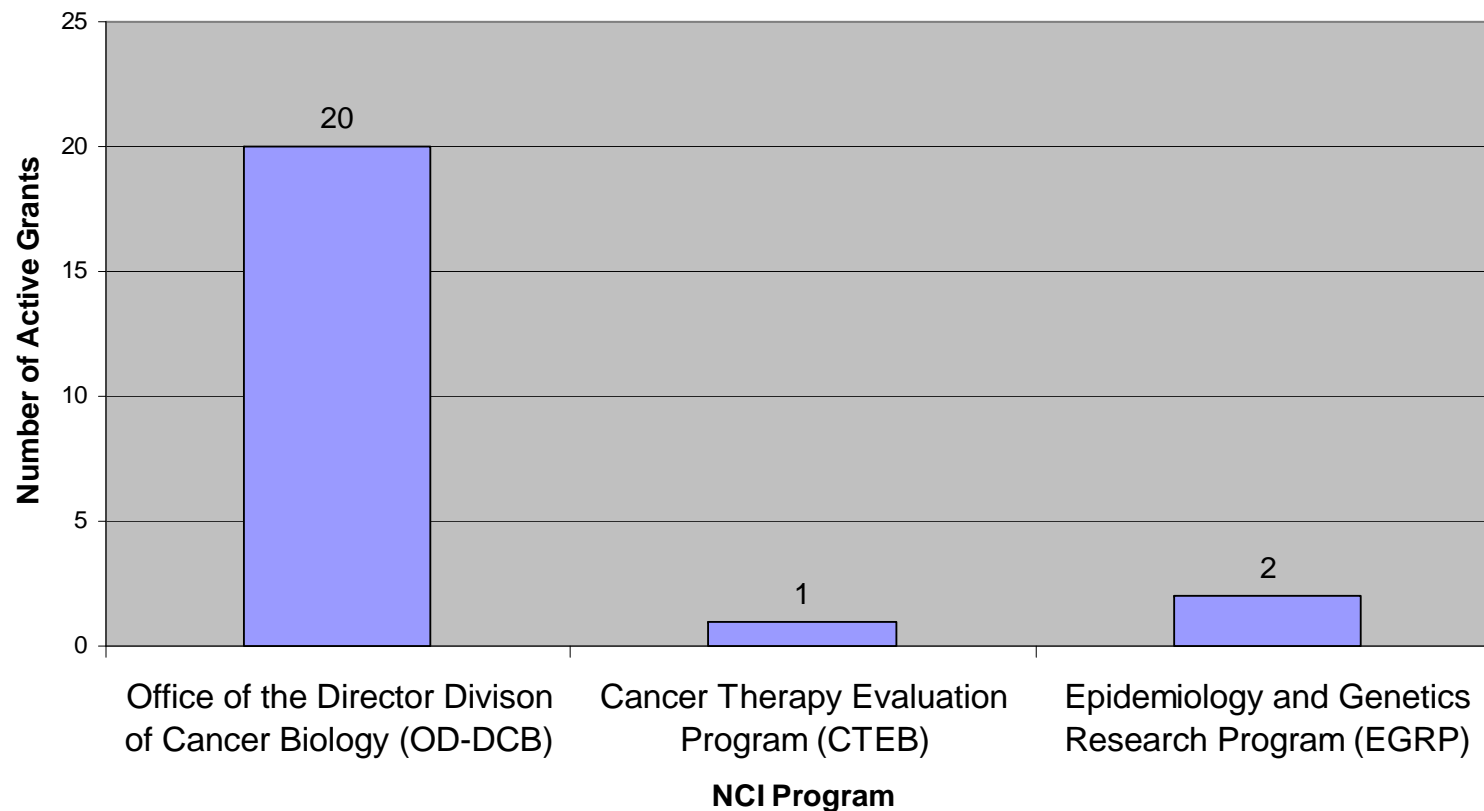
Writer: Shannon Lynch

Background

- Sarcomas are malignant tumors of the connective tissue {bone and soft tissue}
- More than 100 subtypes that affect fat, muscle, blood vessel, bone, etc.
- They constitute approximately 1% of all cancers in adults and approximately 15% - 20% of all childhood cancers
- Many are resistant to current treatment modalities (i.e., surgery, radiation and chemotherapy)

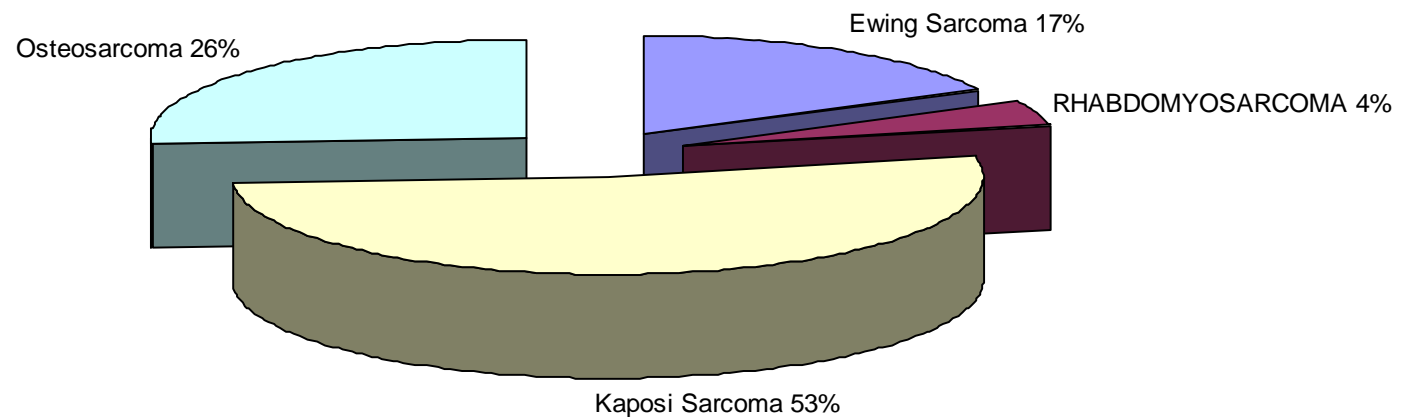
NCI Portfolio Analysis on Sarcoma

Active Sarcoma Grants at the National Cancer Institute (NCI)
(n=23)



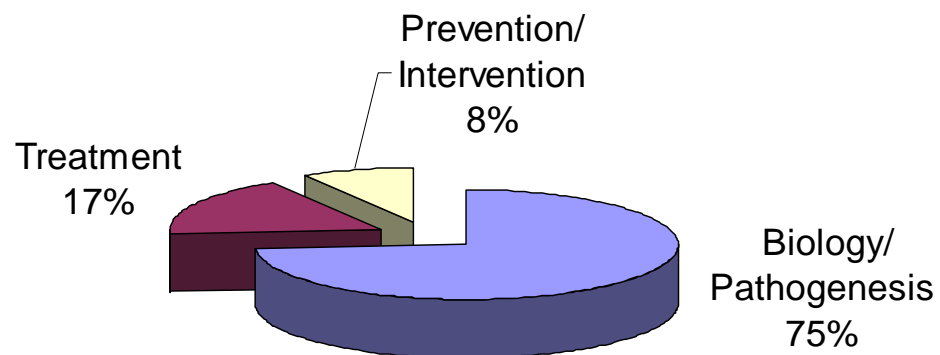
NCI Portfolio Analysis on Sarcoma

NCI Supported Grants on Sarcoma (n=23): Types of Sarcomas Studied



NCI Portfolio Analysis on Sarcoma Grants

**NCI Supported Sarcoma Grants (n=23)
Outcomes Studied**



Research Advances and Gaps: What are the advances in research in this area?

- Etiology of some Sarcomas
 - Kaposi related to HSV-8
 - Chromosomal translocations
- Treatment
- More work to do!

Research Advances and Gaps: What are the highest research priorities in this area?

Short term priorities:

- Identify resources for case ascertainment (existing/new)
- Pilot study funding
- Form a Sarcoma working group with a lead investigator or co-lead

Long term priorities:

- Form an international Sarcoma Consortium
- Funding

Research Advances and Gaps: What scientific gaps need to be addressed?

- Sarcomas in general are very heterogenous
- Adult Sarcomas not well-studied
- Biomarkers
- Limited Tissue collection at diagnosis
- Inconsistency in studies looking at growth and puberty
- Few young adults in studies

Research Advances and Gaps: What scientific gaps need to be addressed?

- Control Selection
- Where to identify cases?
- Variability among pathology and diagnostic techniques

Research Obstacles and Challenges: What are the main obstacles in research in this area?

- Rarity, would need a “Super-Consortium”
- Heterogeneity
- Funding
- Not Sexy
- Very few existing studies focusing on etiology

Research Obstacles and Challenges: How can we overcome such obstacles?

- Identify existing studies and resources
 - Merge biobank data

How can we overcome such obstacles? What type of collaborations are most fitting ?

- Collaborating with existing consortia and others
 - AIDS Malignancy Consortium (AIMS)
<http://pub.emmes.com/study/amc/public/index.htm>
Contact: rmistsuya@mednet.ucla.edu
 - Cancer Genetics Network
<http://epi.grants.cancer.gov/CGN/>
Contact: Carol Kasten; kastenca@mail.nih.gov
 - International Childhood Cancer Cohort Consortium (I4C)
Contact: Terry Dwyer T.Dwyer@utas.edu.au

Collaborations:

What type of collaborations are most fitting for this area?

- HMO Cancer Research Network
- SARC Consortium
- Children's Oncology Network
- Work with Advocacy Groups
- Collaborations between multiple disciplines, i.e. building communication infrastructures

Next Steps:

What do you see as the next steps to foster research in this area (i.e. by NCI, investigators, advocacy groups, etc.)?

- Form investigator working groups
 - Identify a lead
- Get NCI involvement in working groups
- Get grassroot organizations involved
- Recognize sarcoma etiologic studies are in their infancy

2005 Recommendations from the NCI/ORD Sponsored Rare Cancers Meeting

- Develop consortium
- Establish international research sites
- Establish cancer registries in developing sites
- Develop working groups focusing on different areas such as epidemiology, animal models and treatment
- Access to prediagnostic specimens from cohort studies
- Support whole genome studies and other new technologies-encourage novel study designs

Sarcoma Working Group Members

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- Julie Ross
- Greta Bunin
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